

Connecticut General Assembly – Human Services Committee Public Hearing – February 7, 2023

Testimony of Laura Hoch, Senior Manager of Advocacy, National MS Society

Senator Lesser, Representative Gilchrest, Senator Seminara, Representative Case and Members of the Human Services Committee, thank you for the opportunity to provide testimony on SB 82, An Act Eliminating Income and Asset Limits for the Med-Connect Health Insurance Program for Working Persons with Disabilities, and how it affects those who live with multiple sclerosis.

Multiple sclerosis (MS) is an unpredictable disease of the central nervous system. Currently there is no cure. Symptoms vary from person to person and may include disabling fatigue, mobility challenges, cognitive changes and vision issues. An estimated 1 million people live with MS in the United States. Early diagnosis and treatment are critical to minimize disability. Significant progress is being made to achieve a world free of MS.

MS is an expensive disease, with a 2022 study finding the average total cost of living with the condition to be \$88,487 per year¹. MS disease-modifying therapies (DMTs) are the biggest cost of living with the disease, and individuals with MS spend an average of \$65,612 more on medical costs than individuals who don't have MS. In 2022 the brand median price of MS DMTs was nearly \$94,000. Six of the DMTs have increased in price by more than 200% since they came on the market, with nine now priced at more than \$100,000 per year. In a 2019 survey conducted by the Society, 40% of respondents reported that they have altered the use of their DMTs due to cost by skipping or delaying treatment, taking less

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¹ https://n.neurology.org/content/98/18/e1810



National Multiple Sclerosis Society

than prescribed, or even stopping their treatment altogether². Because of the financial burden placed on people living with MS, many are forced to delay retirement or are less able to save and create a financial safety net for themselves as they age.

We discuss the cost of living with MS because it is relevant to every aspect of a person's life; whether or not they are employed and the type of insurance coverage they receive are factors that can change in a moment. While Med-Connect is a wonderful program, the asset limits set forth can be a hinderance to many. Based on the cost of living with MS, a person could be forced to spend all of their allowable assets in a single calendar year leaving them with nothing to fall back on if they suddenly become too disabled to work or have an emergency medical issue not fully covered. Allowing individuals to build the safety net that could potentially come with no asset limits would not only improve their lives and independence but could potentially save the state money when emergencies do arise.

In closing, I would like to respectfully urge the committee to support SB 82. It is vital that people living with MS and other potentially disabling diseases be provided with the opportunity to safeguard their financial futures.

Should you have any questions or concerns, please feel free to reach out to Laura Hoch at laura.hoch@nmss.org or (860) 913-2550 X52521.

 $^{^{2}\,\}underline{\text{https://nms2cdn.azureedge.net/cmssite/nationalmssociety/media/msnationalfiles/advocacy/nmss-research-report-full-access-to-ms-medications.pdf}$